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Scleroderma

New Zealand support group



Winter 2021

Greetings to you all.

Welcome to our Winter edition of the Scleroderma Newsletter...

We hope everyone is keeping well, keeping safe and keeping warm during this colder season.



We are over halfway through the year now, which seems kind of crazy. Is it just me or is time sure flying by. I hope you are all avoiding the cold and flu bugs that seem to be rife around the place. Poor Tina has been holed up in the hospital with Pneumonia as I write this. Hope you are feeling much better very soon.

We have lots of information to share and news from our members in our Scleroderma Community.

We hear from me with my very first Presidents report and introduction.

Sadly we have Memorials for Beth Richards, Gwenda Molloy & Pat Galvin. We have questions and answers on the **Covid-19 Pfizer vaccine**. We also have some helpful advice and exercises to help keep our hands and faces moving. Living with pain articles, Maori Health Models, a notice for our fundraising calendar, looking for budding artists/photographers. An interesting story from Linda Irvine, and Erena Bruce. A lovely letter to her pet from Susan Butcher. And another helpful hint from Heather Milligan and Susan Butcher.

We have the usual Members News, Useful Websites, and Upcoming Events as well as many other interesting articles.

Members are encouraged to submit any stories, jokes, items of interest they would like to share to keep the newsletter fresh and interesting.

We hope you enjoy reading this issue of the newsletter.

Keep warm and safe everyone.

Warmest regards,

Jenny and Tina

Presidents Report:



July 2021

Hi all, Welcome to our Winter edition. I hope Winter isn't too harsh to you all at the moment and you are keeping well and warm. Don't forget to put those extra layers on when leaving the house.

This is a bit new for me having to write this section of the newsletter, but here goes.

I wish to thank you all for the support I have had in my new role as President for you. I hope I can continue the awesome work that Dianne has been doing for such a number of years. For those of you who don't know me, I live just out of Winton, Southland on a lifestyle block with my hubby, dog and cat; now that the kids are all away working and off to uni. I was diagnosed with Scleroderma in 2009 rather quickly after some pain in my knees. I was fortunate, not like some who have had ongoing problems for years before their diagnosis.

Thank you so much Dianne for all your years of hard work, your supportive and caring nature towards us all, and the bright person on the end of the phone when we go through the daunting diagnosis, and reach out to Scleroderma NZ. You are always so positive and so helpful. You did all the hard yards with setting us up as a National Charity and got us involved with Brett Thombs and SPIN. It is so good for little old New Zealand to be acknowledged from all those different countries. Also, the Medical Board that you made happen to help support us. At times there were lots of stresses, but you always handled yourself in a professional manner. Thank you so much Dianne, and I am sure you will be getting a few phone calls from me with some much-needed advice.

Gordon, thank you for staying on as Treasurer. We know everything is in safe hands with you, and the time you put into the role and also into keeping the Website up to date. It is very much appreciated by us all. I know it can be quite time consuming and wasn't always easy while you were also working. The support you have shown Dianne and the rest of us with everything scleroderma is pretty amazing. Thank you.

Our Vice President's role has gone to Tina McLean. Thank with all my heart for saying yes and taking this on to support me, Tina. We make a pretty good team I think when it comes to the newsletter so I'm sure we will

continue to work well together on this also. You have some wonderful ideas and are very knowledgeable in the places that I may not be. Together we will try to fill those big shoes of Dianne's.

Jane Sainsbury is continuing on as Secretary after starting in the roll last year. Thank you so much Jane for staying on. It's great to know we have someone there to keep us in line with everything and make sure we get it all right. I am so happy to have you on the team and look forward to working with you and keeping in touch.

Thanks also to Cushla Masters and Catherine Thompson who keep us up to date on our Facebook page. It's so good to see the positive bits that you put up on there. Another fantastic platform to spread the awareness of Scleroderma far and wide.

Also, the folks on the committee. There is no committee without you and your ideas and support. So, thank you so much to, Catherine Thompson, Heather Milligan, Maureen Anderson, Linda Bell, Erena Bruce, Adrienne Burleigh, Cushla Masters, Dianne Purdie and Julie Rolston.

A huge welcome to any new members who have joined our group. It is so wonderful to be able to meet up with others who know just what challenges you may be facing. I know it has been pretty tough for some over the last few months with some extra health issues and some sad losses, which is why it is always great to have that positive support from the local groups.

By now quite a few of you will have had your Covid Vaccine. I was encouraged when I received my letter to know that we are continuing to be looked after, with most of us being vaccinated within the next couple of weeks. Even once you have had the vaccine remember to take that cautious approach when out in a public area. Now that our bubble with Australia has burst it will keep people grounded for a bit longer but is far better to be extra cautious.

Keep well and warm and wishing you all the very best of health over the coming months.

Jenny



Memorials

Beth Richards



Obituary:

BETH RICHARDS, TASMAN

The small Scleroderma Support Group in Nelson / Tasman was saddened to lose a key member, Beth Richards, on July 15. She is survived by her loving husband Ron, and a family including three daughters and four grandchildren.

Beth was a truly inspirational woman who was always positive and upbeat, even when she was struggling with health issues related to her Scleroderma and associated PAH symptoms, which affected her lungs and heart. She always had a smile on her face and something positive to say. She was the driving force behind the small local group, keeping in regular contact and arranging regular coffee meetings to keep in touch with other sufferers.

She was well known in the small coastal village of Mapua where she would often be seen zooming down the steep hill to the local shopping centre in her wheelchair, where she greeted everyone with a big smile and patiently answered questions about her condition.

Beth will be greatly missed but never forgotten. Our heartfelt sympathy goes to her family in this difficult time.

'Contributed by the SNZ support group, Nelson'.

RICHARDS, Elisabeth (Beth) (nee Holman):

Unexpectedly but peacefully at home on Thursday, July 15, 2021; aged 68 years. Treasured and much loved wife of Ron. Dearly loved mother and mother-in-law of Craig and Kathryn, Liana and Dave, Derek and Kathryn. Loved nana of Zoe, Pepa, Nikau, and Finn. Beth was very much loved and will be dearly missed by all her family and friends.

A service to celebrate Beth's life will be held at Hope Garden of Remembrance Crematorium Chapel, 95 Clover Road, Hope, on Monday, July 19, at 1.00pm. In lieu of flowers donations to Scleroderma New Zealand would be greatly appreciated and may be left at the service or through their **Givealittle** page: www.givealittle.co.nz/org/sclerodermanz1

Messages to The Richard's Family C/- 41 Nile Street East, Nelson 7010.

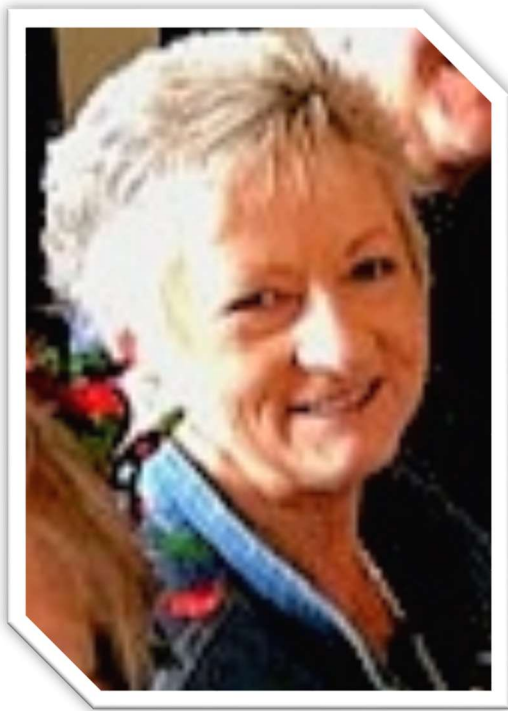
Source:

<https://deaths.nelsonmail.co.nz/obituaries/nelson-mail-nz/obituary.aspx?n=elisabeth-richards&pid=199474779&fhid=12702>



Memorials

Gwenda Molloy



Gwenda was a very kind and caring person. I first met Gwenda years ago when she owned the supermarket and my daughter was a baby and had a mishap while we were shopping. Gwenda took a very stressed, crying Mum into a back room and cleaned me up and made me feel 100% better. Years later she became part of our Southland Group and was such a generous, happy person to be around.

MOLLOY, Gwenda Joy (nee Whyte):

Suddenly but peacefully on Wednesday, July 8, 2021, at home surrounded by her loving family; aged 70 years.

Dearly loved wife and soulmate of Graham. Loved mother and mother-in-law of Lara and Kerrian Simpson, Sasha and Ashley Hunter, Bradley and Anna Molloy. Loved Nannan of Lani, and Casie; Jackson, McKenzie, and Sienna; Jessica, Caleb, and Cody.

"I live for those who love me, for those who know me true"
~ George Banks

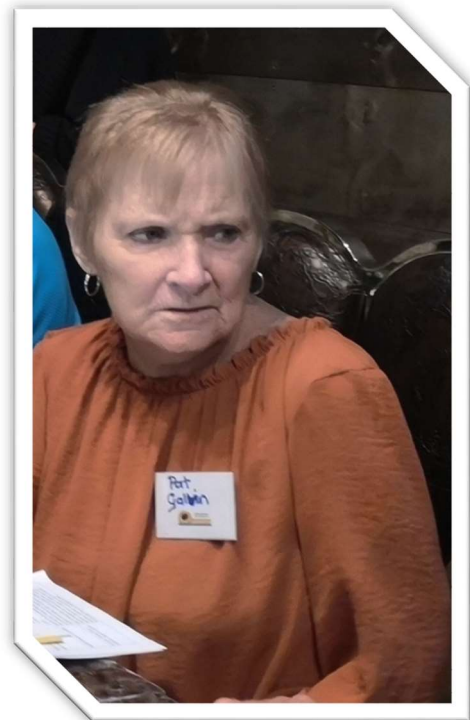
In accordance with Gwenda's wishes a private service has been held. Messages to 32 Talboys Drive, Winton 9720 or on Gwenda's tribute page at:

www.frasersfunerals/tributes

Source:

<https://www.legacy.com/obituaries/southland-times-nz/obituary.aspx?n=gwenda-molloy&pid=199455764>

Pat Galvin



Pat joined our Southland Group a couple of years ago and was such a positive person. She joined in on the zoom meetings and it was lovely to see her smiling face on the computer screen. Nothing was ever a problem and she always saw the best in every situation. Pat had moved into a home but was still looking forward to coming along to our next lunch. She enjoyed meeting with the rest of our group and sharing stories.

GALVIN, Patricia Helena

Peacefully at Gore Hospital, on Sunday, May 23, 2021, aged 73 years.

Adored wife of the late Patrick (Pat), most beautiful Mum and mother-in-law of Theresa and Simon Moriarty (Christchurch), Angie (Gore), Maria Galvin and Garth Stirling (Melbourne), and most awesome Nana of Niamh, Tommy; and Cam. R.I.P. Messages to 217 Lowes Road, Rolleston 7614." Southern Funeral Home

"Donations can be left at the service for the Gore Hospital Whanau Room"

Source:

<https://honourthem.com/obituaries/galvin-patricia-helena-pat/>



Questions and Answers Regarding the COVID-19 Vaccine:

[Read February 10, 2021 guidance on COVID-19 vaccines from the American College of Rheumatology.](#)

*The following information was updated April 29, 2021, by the Scleroderma Foundation's Medical & Scientific Advisory Board Leadership Committee**

Preamble

The COVID-19 pandemic is from the SARS-CoV-2 virus and thus far is responsible for more than 75.2 million cases and 1.67 million deaths worldwide, with 17.3 million cases and 311,000 deaths in the USA (as of Dec 18, 2020). The numbers are rising. COVID-19 is now the leading cause of death in the USA.

Recommendations about receiving COVID-19 vaccinations may be changing as we learn more. These questions and answers are only a guide and should not replace discussion with your health care provider.

The three vaccines approved in North America are the Pfizer, Moderna, and Johnson & Johnson vaccinations. Other vaccines are available in different parts of the world. The Pfizer and Moderna vaccination will be in a series of two injections provided either three weeks (Pfizer) or 28 days (Moderna) apart. The Johnson & Johnson vaccine is a single dose.

If receiving any other vaccine, such as the common flu, a period of 14 days should elapse before receiving either your first or second dose of the COVID-19 vaccine.

Commonly Asked Questions

Should I get the COVID vaccine?

Yes, however if you have systemic sclerosis (scleroderma) there may be some things you should know before you receive it. The vaccines so far have not tested in pregnant women, children below age 16, or large numbers of patients with autoimmune diseases. As more data are available, recommendations may include them.

What is the benefit? The vaccines against COVID-19 seem highly effective. However, they have not been tested in large numbers of people with autoimmune diseases

and/or patients receiving immunosuppressive medications. There may be a dampened response such as in people with systemic sclerosis (scleroderma) who may be taking immunosuppressive medications. The benefits include prevention of COVID-19 infection, or less severe infection, and herd immunity (stopping the spread in your community when enough people are vaccinated). Due to the significant amount of people who have died or been very sick with COVID-19, the hope is to prevent severe infection and its long-term effects.

What do I do with my medications/drugs when I get the vaccination?

At this time, there is not enough information regarding the effect of immunosuppressive medications on the efficacy of the COVID-19 vaccine, and you should consult your health care provider on this matter. Some medications may be interrupted briefly during vaccination, however if you have been on prednisone for a long time, it cannot be stopped for the vaccination.

We know that with the flu shot, patients receiving methotrexate may have a better response if they hold their methotrexate for 2 doses after receiving the vaccination. There is no firm recommendation for the COVID-19 vaccination but perhaps interrupting your immune suppression medication for 2 weeks after each injection may lead to a better response. However, this is only speculation. This could include methotrexate, mycophenolate mofetil, azathioprine, tocilizumab, JAK kinase inhibitors, TNF inhibitors, abatacept. If you are receiving rituximab, the timing may be best to receive the vaccination 4 months after the last dose of rituximab and waiting a couple of months to receive your next dose of rituximab. This is only a guideline and you can show this as an example to your health care provider.

Will this flare my scleroderma?

We do not know, but a flare of scleroderma should not be common as many other vaccinations that boost the immune system do not routinely flare autoimmune diseases in the vast majority of people who receive vaccines.



Questions and Answers Regarding the COVID-19 Vaccine: continued....

The vaccine will not be 100% effective, so all recommendations after being vaccinated will still be present such as wearing a mask, frequent hand washing, and social distancing.

Is there a special risk for me as I have SSc?

The main risk factors for poor outcomes with COVID-19 infection are advanced age, heart disease, chronic obstructive lung disease, diabetes mellitus, high dose prednisone use, and other minor risk factors such as high blood pressure and high body mass index (obesity). It is likely that those with recurrent infections and those who are frail also have a higher risk of doing poorly. We suspect that having interstitial lung disease or pulmonary hypertension or recurrent aspiration from poor motility of the swallowing tube (esophagus) put those with systemic sclerosis at a higher risk, making vaccination an important consideration for these and most other patients. The risk is likely not increased in those with morphea and linear scleroderma unless they are on strong immune suppression treatment.

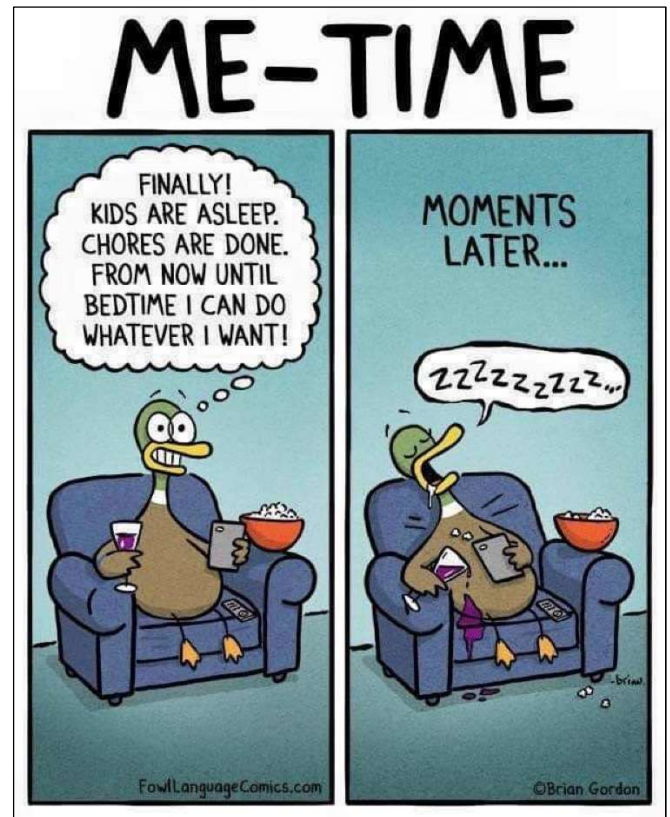
How long will the vaccine be effective for?

We do not know. The vaccine trials contained large numbers of patients, so antibody response and the safety are known for the short term, but the long-term benefit is currently unknown.

Will vaccines stop the pandemic?

This depends on how effective the vaccines are and how many people receive the vaccine (for herd immunity) and how long the benefit / response to the vaccination lasts. Also, so far, the virus is not mutating very much but if it mutates then benefit may be less. This is true for the flu vaccination where the influenza virus mutates every year, and the flu shot reflects the strains that are expected to be in your community.

Scleroderma Foundation Disclaimer: The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials or studies referenced in this document. Information is provided to keep the readers informed. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician for proper evaluation and treatment.



TRUE FRIENDSHIP

Two very elderly ladies were enjoying the sunshine on a park bench in Nelson. They had been meeting there every sunny day, for over 12 years, chatting and enjoying each other's friendship.

One day, the younger of the two ladies, turns to the other and says, "Please don't be angry with me dear, but I am embarrassed. After all these years, what is your name? I am trying to remember, but I just can't."

The older friend stares at her, looking very distressed, says nothing for two minutes, and finally with tearful eyes, says.

"How soon do you have to know?"



Exercises for the hands:

Do each exercise 3 to 5 times and hold for 3 to 5 seconds

Make a fist emphasizing flexion (bending) of the MCP joints. If necessary, the heel of one hand may have to press down on the dorsum (upper surface) of the proximal phalanges of the other hand.



To encourage PIP extension or straightening, you can use the heel of one hand to press the fingers of the other hand flat down against a table, or place the hands and fingers flat against each other in a "prayer" position.



Another exercise for the PIP joint uses 3 points of pressure (see picture). The first point of pressure is the pad of the index finger on the palm side of the finger, just above the PIP joint. The second point of pressure is the pad of the third finger on the palm side of the contracted finger below the PIP joint. The third point of pressure is the thumb against the back of the contracted PIP joint. The thumb pushes against the joint while the index and middle fingers apply counter pressure to attempt to straighten the joint.



To maintain thumb motion, try to bend the thumb to touch the base of the little finger.



To stretch out the thumb away from the hand, place the pads of the thumb and index fingers of both hands together and push the thumbs away from the index fingers.



Oral Exercises:

Sometimes it can be very hard to open your mouth and brush all the parts of your teeth. It can also be very hard for the dentist and dental hygienist to work in your mouth. Before brushing your teeth or just before the dentist/hygienist examines you, there are several exercises you can do to try to stretch your mouth.

Why should I do exercises for my face and mouth? In scleroderma, the skin on the face becomes tight and shiny and results in a mask-like appearance and decreased mouth opening, or microstomia. Being able to open your mouth is important to be able to eat, talk, brush and floss your teeth, and have the dentist work on your teeth.

Exercises to stretch the mouth and face



Exaggerated facial movements consist of pursing the lips, puffing out the cheeks, smiling, and making other expressions in an

exaggerated fashion. These exercises can be done in the shower under warm water. **Manual stretching** uses the hands to stretch the oral tissues. The picture above shows manual stretching. The right thumb is placed in the corner of the left side of the mouth while the left thumb is placed in the corner of the right side of the mouth. The mouth is stretched to the sides by the thumbs. This is a good exercise to do in the shower under warm water.



Oral augmentation exercises with tongue depressors.

Oral augmentation consists of inserting tongue depressors between the teeth from the front of the left side of the mouth to the back of the right side of the mouth (see photo). The position is held for several seconds. The tongue depressors should be held together with a rubber band. You may only be able to do this exercise with a few tongue depressors. Additional tongue depressors can be added as motion increases. Do this exercise sitting.

- Individuals with systemic sclerosis can monitor their own mouth opening by marking the distance between the upper and lower teeth on an index card. The card can be held up to the teeth while standing in front of a mirror.

Source: *Self Manage Scleroderma Website*
Module: *Mouth and Teeth Care*

Janet L. Poole, PhD, OTR/L with input from David M. Leader, DMD, MPH



Living with Pain:

Lori Davis: - Arthritis NZ Educator talked to the Wellington Scleroderma group about Coping with a Chronic Condition" which included living with Pain..

Living with pain can be the hardest part of having arthritis. It's easy to start avoiding activities because they're painful or because you think they may be damaging your joints. You may start losing confidence and feel that life is no longer enjoyable.

Pain is a normal, complex human experience. Short term acute pain is very useful – it's a signal that you need to protect whatever part of your body is hurting. Chronic pain that lasts longer than three months is a different story. It doesn't always signal continuing harm or damage; it may just mean that the nerve pathways have become sensitised and your brain is overprotecting you.

The degree of pain does not necessarily relate to the severity of injury or joint damage. Pain doesn't show up on X-rays or scans! And chronic pain may not respond to standard medical treatment.

We also know that pain, stress, fatigue or depression often make pain worse and create what can feel like a never-ending cycle of pain.

The good news is that this cycle can be broken. The first step is acceptance, which doesn't mean giving up. It's about recognising that you can take control and learn how you can better manage pain yourself. Everybody is different, so be prepared to try various techniques until you find what works best for you.

Pain may limit some of the things you do but it doesn't have to control your life.

Tips for managing pain

- Gentle exercise and stretching
- Maintain a healthy weight and eat healthy foods
- Protect joints by using devices such as walking sticks and supportive, cushioned footwear
- Mind-based approaches (deep breathing, relaxation, mindfulness, distraction)
- Relieve stress: pace yourself, prioritise, plan, watch your posture
- Use medications, topical creams and gels
- Apply heat or cold – whichever brings relief
- Complementary therapies such as acupuncture, massage, yoga, aromatherapy.

The four Ps

These strategies will help you manage your energy levels and your pain:

Pacing – Do you do too much on 'good' days and spend 'bad' days recovering? Pacing is about taking a 'little and often' approach, not tackling activities all at once. Know your limits (or set a timer), change jobs frequently and take regular breaks.

Planning – work out what you need to do each day or week but remember to be flexible. Plan rest times, break tasks into smaller chunks and decide what you can delegate to others.

Priorities – set realistic goals and don't be too hard on yourself. Decide what you have to do today, what you could do today and what you would like to do today but is not essential. Learn to say no, and ask for help when you need it.

Posture – poor posture increases fatigue. Good posture protects your joints and reduces tension on muscles. Try to be aware of how your body is positioned and don't hold any one position for too long. Keep moving!

Source: <https://www.arthritis.org.nz/your-arthritis/living-well-with-arthritis/living-with-pain/>



Facts about pain in scleroderma



- 1 Between **60%** and **83%** of people with scleroderma report that they experience pain at any given time.
- 2 **Sources of pain** in scleroderma include:
 - Raynaud's phenomenon
 - Gastrointestinal pain
 - Joint and musculoskeletal pain
 - Skin pain
 - Pain caused by calcinosis and ulcers
- 3 Levels of pain in scleroderma are similar to those experienced by patients with **chronic pain** and **other rheumatic conditions**.
- 4 Pain levels in scleroderma are associated with **sleep problems, fatigue, symptoms of depression**, and **reduced ability to perform daily activities**.

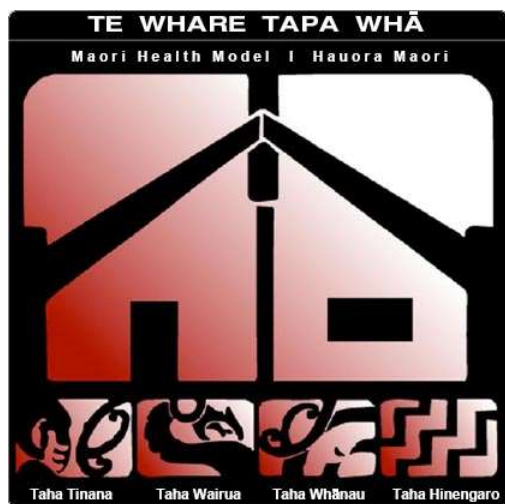
What strategies do **you** use to cope with pain?



Māori health models – Te Whare Tapa Whā

Lori Davis: - Arthritis NZ Educator also talked to the Wellington Scleroderma group about the Te Whare Tapa Whā model, other members may be interested to read it here...

One model for understanding Māori health is the concept of 'te whare tapa whā' – the four cornerstones (or sides) of Māori health.



With its strong foundations and four equal sides, the symbol of the wharenui illustrates the four dimensions of Māori well-being.

Should one of the four dimensions be missing or in some way damaged, a person, or a collective may become 'unbalanced' and subsequently unwell.

For many Māori modern health services lack recognition of taha wairua (the spiritual dimension). In a traditional Māori approach, the inclusion of the wairua, the role of the whānau (family) and the balance of the hinengaro (mind) are as important as the physical manifestations of illness.

Taha tinana (physical health)



The capacity for physical growth and development.

Good physical health is required for optimal development.

Our physical 'being' supports our essence and shelters us from the external environment. For Māori the physical dimension is just one aspect of health and well-being and cannot be separated from the aspect of mind, spirit and family.

Taha wairua (spiritual health)



The capacity for faith and wider communication.

Health is related to unseen and unspoken energies.

The spiritual essence of a person is their life force. This determines us as individuals and as a collective, who and what we are, where we have come from and where we are going.

A traditional Māori analysis of physical manifestations of illness will focus on the wairua or spirit, to determine whether damage here could be a contributing factor.

Taha whānau (family health)



The capacity to belong, to care and to share where individuals are part of wider social systems.

Whānau provides us with the strength to be who we are. This is the link to our ancestors, our ties with the past, the present and the future.

Understanding the importance of whānau and how whānau (family) can contribute to illness and assist in curing illness is fundamental to understanding Māori health issues.

Taha hinengaro (mental health)



The capacity to communicate, to think and to feel mind and body are inseparable.

Thoughts, feelings and emotions are integral components of the body and soul.

This is about how we see ourselves in this universe, our interaction with that which is uniquely Māori and the perception that others have of us.

This model was developed by **Mason Durie**.

Source: <https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha>



Māori health models

Te Wheke

Traditional Māori health acknowledges the link between the mind, the spirit, the human connection with whānau, and the physical world in a way that is seamless and uncontrived. Until the introduction of Western medicine there was no division between them.



The concept of Te Wheke, the octopus, is to define family health. The head of the octopus represents te whānau, the eyes of the octopus as waiora (total wellbeing for the individual and family) and each of the eight tentacles representing a specific dimension of health. The dimensions are interwoven and this represents the close relationship of the tentacles.

- **Te whānau** – the family
- **Waiora** – total wellbeing for the individual and family
- **Wairuatanga** – spirituality
- **Hinengaro** – the mind
- **Taha tinana** – physical wellbeing
- **Whanaungatanga** - extended family
- **Mauri** – life force in people and objects
- **Mana ake** – unique identity of individuals and family
- **Hā a koro ma, a kui ma** – breath of life from forbearers
- **Whatumanawa** – the open and healthy expression of emotion

This model was developed by **Rose Pere**.

Source:

<https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-wheke>

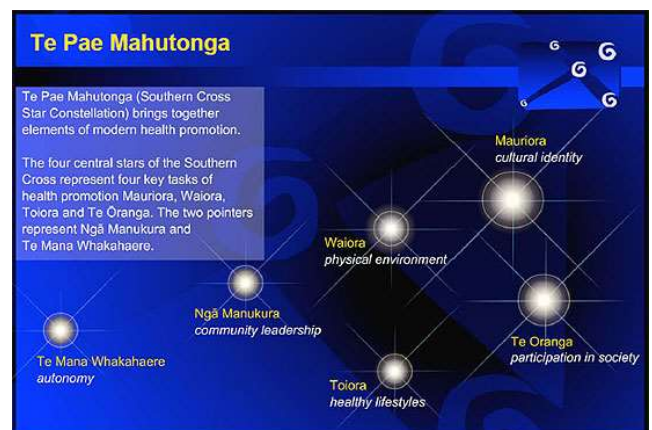
Te Pae Mahutonga

Te Pae Mahutonga (Southern Cross Star Constellation) brings together elements of modern health promotion.

In the diagram below, the four central stars of the Southern Cross represent four key tasks of health promotion:

- **Mauriora** (cultural identity)
- **Waiora** (physical environment)
- **Toiora** (healthy lifestyles)
- **Te Oranga** (participation in society)

The two pointers represent Ngā Manukura (community leadership) and Te Mana Whakahaere (autonomy).



This model was developed by **Mason Durie**.

Source:

<https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-pae-mahutonga>





Scleroderma
New Zealand Inc



ARTISTS/PHOTOGRAPHERS

Fundraising opportunity



February 2022

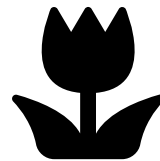
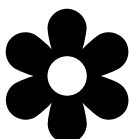
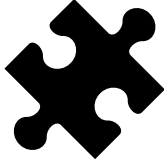
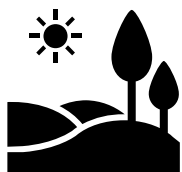
Sun	Mon	Tue	Wed	Thu	Fri	Sat
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28				

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We are looking for artists among you to supply a copy of your work that we can turn into a calendar

This can be a painting, drawing, sketch, photography, a photo of your knitting, crochet, weaving, patchwork, your garden, really it can be anything. Something that will look nice on the wall. We will need at least 12 different things. Please email to jennyred@xtra.co.nz



Members Stories:

Erena Bruce – Hibernation....are we nearly there yet!

Ko te wa o te Matariki, the time of Pilaides.

A time to plan for a new year, a time to reflect, a time to reap the harvesting of our food gardens, fruit trees, preserves, pickles yum.

Yes indeed Winter has been present, we here in Waipa, have hibernated as much as we could. Layers upon layers, accessories to add not only colour but warmth. We have had the snow winds, heavy downpours, you name it; we have had a smidgeon compared to our southern compatriots....all the very best in the West Coast and Canterbury regions in their flood recovery.

So what's happening here in Cambridge, well we have had one get together at Lilipad cafe and lots of text conversations keeping in touch with our various rollercoaster conditions! We all have Systemic Scleroderma, all have Raynards, some gastric and digestive issues that we are managing the best over Winter.

We have been fortunate enough to meet up with a newbie to our group, joining us from Te Awamutu an ex nurse Jill Davies. What a ball of energy, Jill came bounding into our get together. Great stories shared, very medically minded with familiarity of medications we were taking and just an easy flow of our shared diagnosis.

Thanks to Jenny we are also looking forward to meeting another new recruit who has moved up from Invercargill. Lots of Winter bugs about is keeping our meeting up..... pending, but regular contact has been established, cheers Jenny. Invercargill Scleroderma group, so grateful we can network from one end of Aotearoa to the other. Be good to chat about my early days in Invercargill!

As we turn to August and contemplate the gardens warming and prepare for planting it, it would be great to see those bulb colours come through, the wet rain dry off the outdoor chairs and the starry skies open up for viewing again. But to be clear folks we have found the strains of colder and unpredictable winds a challenge, from using opossum gloves, nifedipine tablets, battery powered gloves and socks just to take the chill out of the hands is the reality.....use of electric throws, blankets and endless heat bags to cuddle into again our reality, the physio exercises (to move or loose tendon and muscle use) keeping to gluten free options as best you can, limiting

processed sugars and dairy our reality, I have to use hand splints to support the finger joint inflammation and to avoid too much curling it's a bit of an adjustment, I guess but not a lot of choice really. I have been lucky in Winter I have sheep skin splints! I have also had great success with shoulders and the calcification problem that led to limited movement.

Actually, one experience worth sharing is, about 6-8 weeks ago I was being consistent with physio exercising and I started to get a sore and numbing pain on left cheek left side of face including jaw. GP put me on antibiotics and codeine (for the pain, never again, a nightmare!) and also advised go and see my dentist and check gums and teeth. I had some physio done on neck as he felt tension. My dentist confirmed not gums not teeth likely stress and TM joint he put me on paradine. This went on for two unbearable weeks, managing lots of things on the go never a good thing. Anyhow one day I woke and pain had subsided on the side of my face, another week or so bowels came right (I thought child bearing was bad enough) anyhow the point of this sharing is to advise you all to persevere with where the pain is....if neck pain is deferred pain it should not be intense and should fade with paradine...if not like in my case it was my tooth! Turns out I have a dead tooth that is showing swelling it needs antibiotics, nerve removal and root canal treatment (because I am choosing to keep the only molar tooth bottom lower jaw). Likely the abscess was there a long time ago (6-8 weeks) and unless swelling is evident...only an x-ray will pick it up. I should have insisted to have an x-ray and pushed the teeth were the problem at my dentist. Only consolation now is he did an \$80 panoramic x-ray for free and he will crown the tooth for free, turns out the tooth is great but the nerve and root canal need opening up, cleaning out and filling in again all for a mere \$1050. I know now I shouldn't second guess my own intuition.

Keep well folks, look forward to reading your stories

Nga Manaakitanga,

Erena



Members Stories:

Linda Irvine – Love of cars

Having been born into a family heavily involved with veteran and vintage cars it was only natural that eventually I would own my own, as my siblings have all done.

When my father died I inherited his 1937 Chev Coupe which is all registered and warranted but unfortunately it only does 14 miles to the gallon and on many occasions I have run out of petrol.

So in 2015 I purchased a 1961 MK 2 Zephyr and joined the Southland Zodiac and Zephyr Club.



The car needed a bit of TLC – the seats were all ripped and covered in a blanket, lounge axminster carpet covered the floor and it required a general tidy up. I am lucky in the fact that my son in law is a qualified mechanic and as I store 3 of his cars in my garage in return he keeps my toys on the road.

As the MK 2 has a heater which at present can't be turned off I am still all rugged up when driving and never short of a passenger. I am in no hurry to get the heater repaired.

I am on the Southland clubs outings committee which involves helping to organise car runs usually with a meal involved at a tavern or hotel somewhere and ringing around members. We try and have monthly runs in the summer months and as there are many private collections of cars or memorabilia around Southland these are always of interest to visit.

As I am on my own, when we go on runs members make sure I am always in the middle with other club cars in front and there is always a "tail gate Charlie" behind me. Yearly connections are held by a nominated New Zealand club and you know a year in advance where the

next one is to be held. I have driven the MK 2 to Cromwell, Christchurch, Oamaru and at the end of May this year 8 cars left Invercargill on a Friday morning and went to Timaru as the South Canterbury club was having a 30 year Anniversary weekend. This was a great weekend even though it rained all the time we were there, unfortunately there was flooding so as soon as good byes were said we headed for home.

These weekends usually involve a get together (Friday night) Car run Saturday and Dine and Dance at night, Sunday a Dinner at night and Monday mornings say your good byes and have coffee and muffins, when we all look forward to meeting up with everyone again at the next Connection or Anniversary

Easter 2022 all going to plan we are off to Franz Joseph.

A Southland club member who moved to Christchurch advertised his 1954 MK 1 Convertible for sale, so November last year towing a salvage trailer, my daughter, son in law and granddaughter headed for Christchurch. Needless to say I am now the proud owner.

Linda



Members News:

Southland Scleroderma Group

Heather Milligan bring us up-to-date with happenings from down in Southland...

The Southland Group met on 16 May; it was an intimate group of 7. We enjoyed a yummy lunch with lots of seafood chowder ordered off the menu. We reflected together and thought of the members from our group who aren't doing so well. We went around the table and told each other something positive that is going on in our lives. From Old Zephyr cars, vintage tractors, to new curtains, and mahjong. It is always good to take the time to be thankful even for that small something. Unfortunately, Heather came down with a cold and didn't make it so the photo was missed as the rest of us are totally hopeless at remembering. ☺ **Jenny**

Scleroderma Day a bit late in Southland. We celebrated on the 4th July, a wee bit later than 'World Scleroderma Day on the 29th June'

Jenny, our new President of Scleroderma NZ Inc. welcomed us to her exquisite home, she was a charming hostess and lovely to meet her daughter Maddy and dog Taz, (who featured in the Winter 2020 newsletter). We had a lovely choice of 'pot luck' afternoon tea brought by the attendees, the most impressive was a delicious sponge cake courtesy of Lorraine, who nonchalantly said she had whipped it up that morning between church and lunch! We congratulated Jenny for putting herself as President of Scleroderma NZ Inc and reminded her we are at her beck and call if she needs assistance in the future.

We acknowledged several members who were unable to attend because of health issues, we do hope that we will see them in the future. A doctor, who is not involved in Scleroderma, had recently commented to me that every health problem is made worse by Scleroderma, I know many of you will agree with this.

Our main topic of conversation was the seminar we plan to hold in March 2022. Jenny had already sketched out the organisation for the seminar, it had been planned to be held in September 2020, but had been postponed. I am sure you will be kept up to date on the event and hope to see lots of you there.

Our next get together is on Sunday 22nd Aug 2021 at Gore. Looking forward to it already.

Thank you again Jenny for your excellent organisational skills and best wishes for your work on the SPIN course for the next few weeks.

Heather



Linda, Kim and Clare arriving in style to our latest afternoon tea

Linda, Kim, Terry, Jenny, Heather, Ian and Barney



Graham, Betty, Glenys, Clare & Lorraine



Members News:

Wellington Scleroderma Group

Dianne Purdie bring us up-to-date with happenings from their Wellington Meeting on the 15th of May...

Wellington got together in May for our Quarterly meeting. We were fortunate to have two Educators from Arthritis New Zealand talking to us about how to cope with chronic pain. Chronic pain seemed to be the most popular problem that the Wellington members had. The Educators went through the process of pain management along with a number of techniques including exercises for coping with pain. If you go to the following link, you can learn all the tips for yourselves. Well worth the look.

<https://www.arthritis.org.nz/your-arthritis/living-well-with-arthritis/living-with-pain/>

The Educators also had a number of hand knitted gloves and hats for sale as a fundraiser for Arthritis New Zealand. Most of us brought a great pair of gloves, a hat or a blanket for a good price of \$10-00. These items were knitted by volunteers for Arthritis New Zealand.

We concluded the afternoon with a lovely afternoon tea provided by our members.

Some images of Exercises from the Arthritis NZ booklet.



Dianne and Lori Davis



Catherine and Lori



Tory and Lori – Arthritis NZ Educators display knitted items



Paul checking items for sale



Wellington members listening to Lori Davis, Arthritis NZ Educator



Members News:

Wellington Scleroderma Group

Notes taken by Tina McLean from the Wellington Meeting on the 15th of May

We had a lovely get together with good turn out from the Wellington members to listen to Arthritis NZ presenters **Lori Davis** – Arthritis NZ Educator and **Tory Garnham** - National Volunteer Coordinator, talk to us about “**Coping with a Chronic Condition.**”

Lori covered various topics in her presentation, which I tried my best to capture in this summary. Some of the topics Lori covered have already been included as separate articles in the earlier section of this newsletter.



Lori talked about Inflammatory and Non-Inflammatory diets. The key here is to observe what triggers inflammation.

You are your own best Health Expert, so be your own advocate and find a good GP to go on the journey with you.

Lori suggested using smart phone Apps for goal setting.

Lori also mentioned “**Cognitive Behavioral Therapy (CBT)** - a communication therapy that aims to help you change your thinking in order to change your behavior. Distraction is a technique used to stop catastrophic thoughts.



All in all, it was a very interesting and informative talk and I think each one of us went away from the meeting learning something useful.

Take care everyone and keep warm,
Tina McLean



Waikato Scleroderma Group

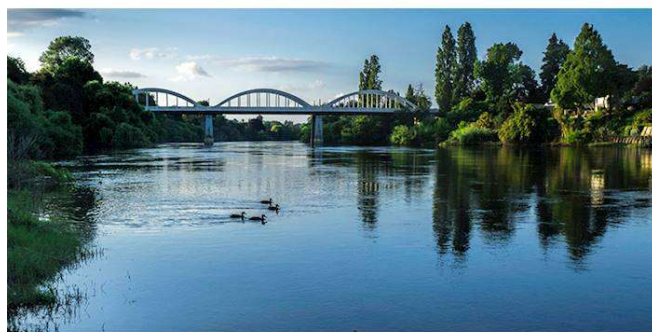
We had a lovely time at our Luncheon at the Golf Club for Scleroderma Day. It was great to get together with our group and the Cambridge group joined us as well. It was a wonderful venue and wonderful company. Talking to Linda Bell, she summed things up pretty nicely ‘Scleroderma is like a roller coaster’

The Waikato/Cambridge/Waipā groups are organising a day for some time in October/November 2021. This will be dependent on speakers and the response from the Medical people in that area as to whether they will be doing a seminar for the day or an more informal morning tea. They were unable to pin them down and get the details sorted before we went to print so just keep that in mind and we will bring you more details in the next newsletter.



Waipā

Cambridge



Waikato



Members News

Christchurch Scleroderma Group



Here's a photo of our Group, from left -
Chris Bates, Glynis Hemi, Carolyn Barkhausen, Julie James, Carla Martin, Nikki Moore, Barbara Dench and Janine Collings.

Hello from the Christchurch Scleroderma Group. We had a fantastic meeting on 29th May at the cafe in Burwood Hospital. We are beginning to be recognised by our sunflower attire! People are not shy in asking who we are - and we give out newsletters to those interested, so hopefully we are spreading the word about Scleroderma.

Unfortunately Maureen Small from Ashburton was unable to attend because of the floods.

We are delighted to welcome two new members, Rane Brady and Annette Marsden who will be joining us at the lunch on 31st July at the Garden Restaurant. We are so looking forward to meeting you.

A very big thank you to our members for their enthusiasm and support. We love our meetings which are full of talk and laughter.

Carolyn

Members Tips:

Heather Milligan – Toothpaste trick...

Yes, you can groan and say, 'What another Heather Milligan toothpaste article'!!!

I kept looking at my fingernails and cuticles which look grubby, unkempt and shabby. I agreed with my rheumatologist that I would not do anything drastic with them as it is such a delicate area. But what to do? In the bathroom one night a few months ago after cleaning my teeth my brain went into overdrive and thought perhaps toothpaste might be a good cleaner, as it is advertised as whitening your teeth, it could well brighten my nails. I checked with Google and found I was way behind the race as there were 389,000 results all saying yes, a good idea and it won't do your nails any harm. I found an old toothbrush and gently scrub my nail area with toothpaste at night and rinse off after a few minutes. It did take a few weeks to see any difference, but I am so pleased with the results, my nails do look brighter and healthier.

Heather Milligan

Susan Butcher – Dry mouth: A tip from an Oral Hygienist

Look for chewing gum that contains Xylitol for the best outcomes. These gums are generally available from the Warehouse Pharmacy, and maybe other Pharmacies. Remember regular drinks of water too.

Susan Butcher



Members News:

National Zoom Meeting

Our latest Zoom Meetings was on April 17th - an informative one on the morning and a chat in the afternoon....

How to prepare for a Zoom meeting



Entertainment Fundraising Booklet in support for Scleroderma



Linda Bell's Family through their **Target Business** has very kindly set up some fundraising for **Scleroderma NZ** through the Entertainment booklets which is done through your Phone. Please see the attached information. Link below:

<https://www.entertainmentbook.co.nz/orderbooks/935q727>

Many Thanks again Linda and Family for your on-going support, it is much appreciated.

Dianne Purdie

2021 Virtual National Scleroderma Conference

On July 17 & 18, 2021, the "Virtual" National Scleroderma Conference was held.

I was unable to attend at the time due to having my gorgeous Granddaughter but registered and have been working my way through the recorded sessions. Some of which have included:

- The lung in Scleroderma – Dr Kristin Highland
- Localized Scleroderma – Dr Christina Lam & Dr Michael York
- Newly Diagnosed: Scleroderma 101 – Dr Flavia V Castelino
- Covid-19 Update – Dr Robert Spiera & Dr Jessica K Gordon
- Cannabis/Naturopathic Care, What to Know and Ask – JoAnna Harper Pharm.D.

All very interesting but I did get the most out of the newly diagnosed, even though it is 12 years since I was diagnosed. Very informative, has been great to give myself a wee refresher.

Lots still to go through in the next couple of weeks, including:

- Dental Care in Scleroderma – Dr David Leader & Dr Luis Del Castillo
- Predicting Progression in Scleroderma – Dr Laura Hummers
- Scleroderma Test – Dr Rick Silver & MUSC team
- Mental Health in Scleroderma – Ron Sasso M.S
- Wound Care in Scleroderma – Dr Tracy Frech
- Medication's in Scleroderma – Dr Jessica Ferrell



Useful Hints:

Readers you are welcome to submit your favourite recipes, ideas, suggestions and useful hints here...

For Painful Fingers and Hands

You might like to try this once a day

Oil and Rubber Kitchen Gloves

1. Rub a neutral oil on to fingers and hands (e.g., coconut oil, almond oil, cooking oil, baby oil)
2. Put on a pair of rubber kitchen/cleaning gloves
3. Fill a sink or basin with hot tap water. The water can be hotter than you would normally use as your hands are protected by the rubber gloves, but still be careful not to burn yourself (it should not be uncomfortably hot).
4. Soak your hands in the hot water for 10 minutes with the rubber gloves on
5. Take your hands out of the hot water but leave the rubber gloves on for a further 10 minutes
6. Take the rubber gloves off, point fingers to the sky and gently massage in the remaining oil



ARTHRITIS TIPS FOR WINTER

To reduce pain, stiffness and swelling

To support energy, immunity and general well being



1 DRESS WARMLY

- Layer up-so you can peel off as needed
- Leg and knee warmers, warm socks and slippers
- Wrist warmers, compression gloves
- Outerwear-Think of functionality, ease of opening and durability. Hats, scarves, gloves, coats



2 KEEP HYDRATED

- Drink water, soups, non-caffeinated teas



3 STAY ACTIVE

Contact Green Prescription on 0800 228 483 for more information and support around appropriate exercise options for you and what is available in your community.



4 WARM WATER COMFORT

- Hand & Foot soaks
- Hot Packs/hot water bottles
- Warm showers/Baths



5 STAY SAFE

- Walking aids to support safe mobility
- Supportive shoes with good tread



6 MASSAGE/RUB ON CREAMS AND GELS

- Can be warming and soothing



7 ASSISTIVE PRODUCTS

- Check out the wide range of assistive products including aids for daily living and mobility aids
- Independent Living <https://ilsnz.org>
- Mobility Centre <https://www.mobilitycentre.co.nz>

Joke of the day:

HOW TO GIVE YOUR CAT A PILL:

1. Pick cat up and cradle it in the crook of your left arms if holding a baby. Position right forefinger and thumb on either side of cat's mouth and gently apply pressure to cheeks while holding in the right hand. As cat opens mouth, pop pill into mouth. Allow cat to close mouth and swallow.
2. Retrieve pill from floor and cat from behind sofa. Cradle cat in left arm and repeat process.
3. Retrieve cat from bedroom, and throw soggy pill away.
4. Take new pill from foil wrap, cradle cat in left arm, holding rear paws tightly with left hand. Force jaws open and push pill to back of mouth with right forefinger. Hold mouth shut for a count of ten.
5. Retrieve pill from goldfish bowl and cat from top of wardrobe. Call spouse from garden.
6. Kneel on floor with cat wedged firmly between knees, hold front and rear paws. Ignore low growls emitted by cat. Get spouse to hold head firmly with one hand while forcing wooden ruler into mouth. Drop pill down ruler and rub cat's throat vigorously.
7. Retrieve cat from curtain rail, get another pill from foil wrap. Make note to buy a new ruler and repair curtains. Carefully sweep shattered figurines and vases from hearth and set to one side for gluing later.
8. Wrap cat in large towel and get spouse to lie on cat with head just visible from below armpit. Put pill inside end of drinking straw, force mouth open with pencil and blow down drinking straw.
9. Check label to make sure pill not harmful to humans, drink 1 beer to take taste away. Apply Band-Aid to spouse's forearm and remove blood from carpet with cold water and soap.
10. Retrieve Cat from neighbour's shed. Get another pill. Open another beer. Place cat in cupboard, and close door onto neck to leave head showing. Force mouth open with dessert spoon. Flick pill down throat with elastic band.
11. Fetch screwdriver from garage and cupboard door back on hinges. Drink beer first. Fetch bottle of scotch. Pour shot, drink, apply cold compress to cheek and check records for date of last tetanus shot. Apply whiskey compress to cheek to disinfect. Toss back another shot. Throw T-shirt away and fetch new one from bedroom.
12. Call fire brigade to retrieve the f----- cat from tree across the road. Apologize to neighbour who crashed into fence while swerving to avoid cat. Take last pill from foil wrap.
13. Tie the little b***ard's front paws to rear paws with garden twine and bind tightly to leg of dining table, find heavy duty pruning gloves from shed. Push pill into mouth followed by large piece of steak fillet. Be rough about it. Hold head vertically and pour 2 pints of water down throat to wash pill down.
14. Consume remainder of Scotch. Get spouse to drive you to the emergency room, sit quietly while doctor stitches fingers and forearm and remove pill remnants from right eye. Call furniture shop on way home to order new table.
15. Arrange for SPCA to collect "mutant cat from hell" and call local pet shop to see if they have any hamsters.

HOW TO GIVE A DOG A PILL:

1. Wrap it in cheese



Pet Corner:

Susan Butcher shares a letter to her pet...

LETTER TO JACK

Dear Jack,

Jack, you've lived with us for a long time now. Thirteen years, maybe even fourteen? Do you remember the mammoth trip Hugh took to bring you home? You were born in the wilderness, beyond Raetihi, part of a purebred litter of Border Terriers.

We adored you. So cute. Gorgeous warm russet colour, maybe marmalade even. Our wee golden boy, bright eyed, and with the charming habit of cocking your head when we spoke to you. You stole our hearts.

James spread the word at Onslow College that we had a new puppy, cute as a button. And the girls responded. Georgia made James a chocolate cake and came to see you. Rebecca's grandmother made him ginger crunch when she came to see you. Other girls came too; their arms bearing gifts for James, and all wanting that mandatory hold of our wee puppy. You licked their faces and they all laughed with pleasure.

And no matter how much I complained, you still found your way into James' bed in the middle of the night. There you were tucked up, snuggled together.

Hugh complains that you are not allowed on our bed. Forgive me, dear Jack, but a woman has to have some standards.

I know you and I have a less intimate relationship, than the others. Hugh and you go on daily walks; up hills, past scary cattle and cows, all around Ohariu Valley, sometimes even to Makara and back. Makara was a "biggie"; 40ks in a day. And you and Hugh have gone to the top of Mt Climie, but you missed out on the Mt Matthews' walk. When Cathy and Dan visit N.Z., you've trotted beside them, showing Dan the local sites.

Hugh chose you because of your propensity for long walks. As you know, your ancestors were bred to accompany the hunt, keeping up with horses and squirreling down fox holes for your prey.

But our relationship is special too. I'm your chief groomer, # 1 brusher and washer. Our adventures in the laundry involve lots of water, both in the tub, and out. Do you mind my singing nursery rhymes at bath time? Silly, I know, but it's my pathetic attempt at calming you, treating you as my baby. Our other special times (until the Vet put the kybosh on it,) were on crispy winter mornings. You, with your porridge, milk sitting in a bowl on yesterday's newspaper; me, with porridge, milk and today's newspaper. We were a blissful pair.

Jack, did you know you had a predecessor? Polly, a darling black Cocker Spaniel, a gift from Hugh for James' third birthday. James opened the box and announced, "But I want a parrot. Pretty Polly," so Polly she became. What Polly lacked in intellect, she made up for with adoration. She adored Cathy and James. She followed them to Khandallah School, much to Tony Sims' chagrin. She caught the unit to town once, another day she jumped out the car window in anticipation the kids would vacate the car without her. That day, Jack, we were at the corner of Marjoribank Street and Cambridge Terrace and it was a major family crisis. And one more infamous occasion: she took off on her daily walk up Kau Kau, sans Hugh. She got lost, returning the next day. I think, Jack, that our distress over her disappearance is probably the same as what you feel when we drop you at "Boarding School". We know you're not being naughty, nipping at our ankles, ripping my jeans, you're just distressed at being abandoned. We understand that dear boy, but sometimes we

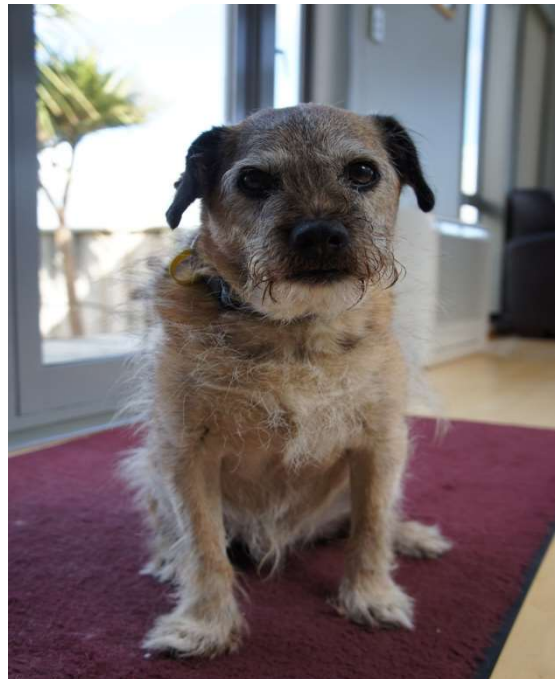
do have to leave you behind. But back to Polly: she's resting now, at the bottom of that pink rose in a pot, the rose called Pretty Polly.

You, darling Jack, have never caused us such moments of stress; i.e. until last Wednesday. How did it all go so terribly wrong? After Monday's northerly storms, our south facing front porch was knee deep in leaves and debris, so I popped out to give it a sweep. You too, popped outside to enjoy the sun, the wind in your fur, the smells from the weeds and wildlife next door, and I left the front door open for your return. Hugh came home, closed the door, and disappeared into his study. I assumed you'd gone there too, after all it is one of your favourite places. Well, some three hours later, Hugh commented how quiet you had been. Hello Jack, where were you? We frantically called you, then drove around the neighbourhood desperate to find you. No Jack anywhere. We returned home knowing you didn't stray far, thinking you just may be caught somewhere in that blackberry infested wilderness next door. We called, we whistled, we called again, and eventually you responded. Just a weak wee whimper, no more. You must be entangled in the blackberry but, dear Jack, we're too old to climb down such a vertical bank. Good old Hugh did clamber around the periphery without success. Finally we called on the local fire brigade who arrived all kitted and with their fire engine. Their youngest guy threw himself down the bank, calling your name as he swung through the bush and vines, but no response from you. And then Jack, and this is the good news, you pootled out of your own accord, gave your coat a good shake and trotted inside to your water bowl. How amazing was that? Forgive me, I must own some embarrassment too. Well we thanked the firemen, and then I went straight inside for two chocolate biscuits and a soak in a long hot bubble bath. The next day I gave the fire guys a dozen beer for their troubles.

And so Jack I must wish you a quiet, peaceful life as you live your twilight years in our company. I promise that you will be protected from nasty adventures, and though the future may contain an arthritic hip, tooth ache and other such infirmities, we will endeavour to support and help you.

You have provided our family and friends with more love and affection than we could have imagined.

With love from your foster mother, Susan



Upcoming Events:

Southland

Is there anyone in the Otago Area who would like to join our group until we can get one up and running in Dunedin? If so please get in touch with either Heather or Jenny.

Heather: milliganseeds@xtra.co.nz

Jenny: jennyred@xtra.co.nz

Waipa

Looking for fellow Scleroderma folk who live in Cambridge, Te Awamutu or even Morrinsville to come and join us. We meet lunch times but are open to meet Saturday afternoons. Depends on what suits really. We chat, share resources, ideas, networks anything really. Open to zoom as well. Let's endeavour to support each other as best we can.

If you would like to join in with the **Waipa** Group, please contact **Erena Bruce**, all welcome.

Email: glenanderena@xtra.co.nz

Mobile: 021 186 9680

Waikato

We normally meet every second month at **Robert Harris Café, Chartwell**

We are looking to have a seminar/Informal morning tea get together with Waipa/Cambridge group around October/November. Just waiting for confirmation. More details to come out in the next newsletter.

Please email linda.bell@hotmail.co.nz

for information..

Phone: 07 8535434

Mobile: 027 548 1214

Christchurch

We are having our next meeting on 31st July, it's a lunch at the Garden Restaurant which should be fun. Hopefully our two new members will be attending!

We welcome any new members to come along too.

Please contact Carolyn **Barkhausen** if you would like to join in with the **Christchurch** Group, you would be most welcome.

Email: barkman@xnet.co.nz

Wellington

Please contact **Dianne Purdie** if you would like to join in, you would be most welcome.

Email: diannepurdie@xtra.co.nz

Thought for the day:



Events & Happenings:



SPECIAL ANNOUNCEMENT:

Southland Scleroderma Seminar 2022

Now that most of us will have been vaccinated within the next few months we have decided to go ahead with our 2020 Seminar. (Only a tad late)

This will now be held on:

Saturday 26th March 2022
at Southland hospital, Invercargill.
It will run from 9am - 3pm with Morning tea, Lunch and Afternoon tea supplied.

More details will come out nearer the time once we sort out the speakers, and finer details.

Please pop it on your calendars and come and join us in the deep south for some education, yummy food and friendship.

NOTICE BOARD...



Southland
Scleroderma Seminar

26th March 2022

Scleroderma
Wellington Support
21st August 2021

Scleroderma
Christchurch Support
31st July 2021

Scleroderma
Southland Support
22nd August 2021

Scleroderma
Waikato Support
10 August 2021

Waikato/Waipa/
Cambridge Seminar

**October/November
2021
To be confirmed**



Noticeboard:

Wellington support group meets:

Saturday 21st Aug 2021 1.30pm to 4.00pm
Saturday 20th Nov 2021 1.30pm to 4.00pm

Venue:

Hardwick Smith Lounge, Belmont Domain, Lower Hutt

Christchurch support group meets:

Saturday 31st July 2021 Lunch at the Garden Restaurant
Saturday 25th Sept 2021 2:00pm to 4:00pm
Saturday 27th Nov 2021 2:00pm to 4:00pm

Venue:

Café, ground floor at Burwood Hospital

Southland support group:

Sunday 22nd Aug 2021 Croydon Lodge Gore
Sunday 28th Nov 2021 Jenny's Place Winton
- Pot luck afternoon tea from 1.30pm onwards

Waikato support group meets:

If you would like to join in with the Hamilton Group, please contact Linda Bell.

Please email linda.bell@hotmail.co.nz to confirm.

Phone: 07 8535434

Mobile: 027 548 1214

We normally meet every second month at Robert Harris Café, Chartwell Hamilton.

Date: 10th August

Place: Robert Harris

Time: 10.00am

New Support Groups:

If you would like a support group in your area please contact: Jenny Andrews 0273 166124 or email jennyred@xtra.co.nz and she will be happy to help you set one up.

Does your area plan a meeting? For times, venue and directions to all meetings that we know about:

www.scleroderma.org.nz/calendar/

Contacts:

Find a Scleroderma a Support Group near You:

Waikato: Linda Bell, Email: linda.bell@hotmail.co.nz

Hawkes Bay: Jane Sainsbury, Email: jsainsbury@xtra.co.nz

Waipa: Erena Bruce, Email: glenanderena@xtra.co.nz

Palmerston North: Dianne Purdie, Email: diannepurdie@xtra.co.nz

Wellington: Dianne Purdie, Email: diannepurdie@xtra.co.nz

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Welcome to Scleroderma New Zealand Inc.

To all our new members, who have recently joined us – Welcome....

Scleroderma New Zealand Inc. is for people with scleroderma and their families and friends. As there are not too many of us, we would like to be able to provide support, friendship, exchange of ideas & information.

Link to our **Website** address below: -

<http://scleroderma.org.nz/>



Link to our **Scleroderma NZ Facebook** page: -

<https://www.facebook.com/SclerodermaNewZealand/>



Link to our **Auckland Facebook** page: -

<https://www.facebook.com/groups/sclero.akl/>



Life begins at 80

I have no idea who wrote the enclosed lines but I recently came across them while tidying my desk. Now I've had my 80th birthday, would like to share them with other readers in this "vintage" age group.

The joys of being 80

I have good news for you – the first 80 years are definitely the worst. The second, so far as my experience goes, is a succession of pardons. If you forget your neighbour's name, forget to fill an appointment, promise to be in two or three places at once or spell words wrongly, you just need to explain that you are 80 years old.

At 80, you can relax with no misgivings. You have a perfect alibi for everything; absolutely everything.

No one expects much of you. If you act silly, it's your second childhood. This is a great deal better than being 70 years old or even 65. At 70, people are mad at you for everything. At 80, they understand and forgive. If you ask me, life begins at 80!

Remember too, old fold are worth a fortune – with silver in their hair, gold in their teeth, stones in their kidneys, lead in their feet and gas in their stomachs.

I have become a little older since last talking to you and a few changes have taken place. Yes, I've become a frivolous old girl. I'm seeing five gentleman a day. On awakening, Will Power helps me get out of bed, Then I pay a visit to John. Arthur Ritis arrives mid-morning. He doesn't like to stay in one place very long so moves around and takes me from joint to joint. Al Zheimer arrives in the afternoon. After such a busy day, I'm really tired and ready to go to bed with Vic Vapo-rub. What an interesting life.

Oh, yes! The preacher came the other day too. He said at my age, I should be thinking about the hereafter, I told him I do – all the time! No matter where I am – in the kitchen, upstairs in the bedroom or down in the garage – I ask myself, "Now, just what am I here after?"

Many thanks to Betty for submitting

<http://scleroderma.org.nz/>



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